Hospice UK’s submission to the UK Government consultation on Changes to the MCA Code of Practice and implementation of the LPS

Hospice UK’s responses to the questions in this consultation can be found below. More information, including the draft Mental Capacity Act 2005 (MCA) Code of Practice and LPS regulations being consulted on, can be found here.

Proposed updates to existing chapters that now include LPS guidance in the Code

- How clear is the guidance in the Code at explaining the interaction between the LPS and other relevant legislation and planning for 16 and 17 year olds?

Somewhat clear.

The guidance in the Code regarding the LPS process for 16 and 17 year olds is somewhat clear. However, it would be useful to have further guidance for health and care staff on the likely impact that involvement with the LPS at home and its associated scrutiny will have on the families of young people subject to deprivation of liberty. This is a new process and therefore will be very challenging for families.

There is the potential that families of young people may not see a situation as a deprivation of liberty or that they might create barriers to health and care professionals carrying out the LPS process, for example, by refusing entry to their home.

Further difficulties may also arise around assessments of young people performed by staff who do not have a personal relationship with the child or palliative care experience. Assessors within the social work profession could also provoke fear in the families of young people, making them worried that their child could be taken away. These challenging scenarios need to be recognised and explored within the Code and its examples.

Proposed updates to the existing guidance in the current MCA Code

- Do any of the updates to the existing guidance in the Code, as listed in Section 1 and Section 2 of the consultation document, require further expansion or revision?

Yes.

Paragraph 11.2 of chapter 11 outlines that young people under the age of 18 cannot make an advance decision but can make an advance (written statement). There is a lack of clarity within this paragraph and throughout the Code regarding the difference between an advance decision and advance statement. We would also recommend clarification regarding the ramifications for health and care professionals who act against the wishes expressed in a non-legally binding advance statement.

People who require palliative and end of life care are likely to be supported by a patchwork of different providers, including general practice, domiciliary care, care homes, district nursing, hospices and NHS trusts. The resulting challenges around integration of services and partnership working mean that health and care workers supporting people with palliative and end of life care needs can struggle to access relevant patient information held by other services. Paragraph 11.3 should be further expanded to explain...
what happens if an advance decision exists but cannot be accessed by health and care professionals when they are making a decision on treatment, for example, if the record of an advance decision is held by a GP surgery and cannot be accessed by out of hours community staff over the weekend.

Chapter 11 would also benefit from [an] example[s] of how advance decisions can be recorded in healthcare records and how proof of an advance decision can be obtained by health and care professionals when it is required.

The new chapters which contain LPS guidance in the Code

- How clear is the guidance in chapter 12 at explaining the meaning of a deprivation of liberty for practitioners?

Very clear.

- The Code sets expectations about how long key LPS processes should take to complete. Specifically, it states that the LPS authorisation should be completed within 21 days and that Responsible Bodies have five days to acknowledge an external referral. Do you think the timeframes set out in the Code are:

Too short.

21 days is an insufficient timeframe for the completion of LPS authorisation. Whilst the ability to rely on existing capacity and medical assessments within the liberty protection safeguards will streamline the process for many clinicians, previous mental capacity assessments are unlikely to be relevant for most patients receiving end of life care. This is because mental capacity fluctuates enormously at end of life. Therefore, it is likely that the specialist palliative and end of life care workforce will need to ensure new capacity assessments, medical assessments and necessary & proportionate assessments are all undertaken when they complete the LPS process for a patient in their care, which will be very time consuming.

Hospices are typically small community-rooted organisations, which are primarily funded by charitable donations and insufficiently resourced to meet the needs of their population. Many hospices will therefore struggle to coordinate the extensive communication with their responsible body that the LPS process requires within 21 days. The patchwork nature of the palliative and end of life care landscape, where most patients will be supported by multiple providers, also means that hospices are likely to spend a significant amount of time chasing other providers for information. For example, requesting a patient’s diagnosis from a GP surgery could take a significant amount of time. If a case is referred to an Approved Mental Capacity Professional (AMCP), this will also increase the time required to undergo the entire LPS process, from identification of a potential or actual deprivation of liberty to authorisation.

- How clear is the guidance in chapter 13 at explaining the interface between the LPS and other health and care assessments and planning?

Somewhat clear.

The guidance is clear that LPS assessments and determinations should be carried out alongside any other ongoing health and care assessments, planning or reviews. However, Chapter 13 contains no guidance for health and care staff on how to coordinate the health and care assessments and planning alongside the LPS. It is essential that local areas create local procedures around how to undergo the LPS
process alongside other assessments and planning and that Responsible Bodies support health and care staff with coordinating this process. This is particularly important for hospices, and other independent providers working across multiple settings and areas, as they are likely to be reporting to multiple Responsible Bodies, which will all need to ensure they don’t fall through the cracks in terms of support.

It is also unclear how Government and the health and care system will ensure there are sufficient staff who are qualified to undertake the LPS process alongside other health and care assessments and planning. The palliative and end of life care sector is experiencing a staffing crisis whilst facing significant demand for its services, due to a high number of undiagnosed conditions during the pandemic, which have resulted in complex palliative care needs, and the UK’s ageing and increasing population. Hospice UK would be happy to discuss measures to help ease the hospice staffing crisis and the importance of a consideration of future palliative care need within workforce planning with officials at the Department of Health and Social Care, as this is a key barrier to the successful implementation of the LPS.

It is important to note that hospices and other specialist palliative and end of life care providers have significant expertise in supporting the people they care for with Advance Care Planning. This expertise should be harnessed by Responsible Bodies and hospices should be highlighted in national guidance as organisations that can support and train generalist staff across the health and care system in future care planning, which places the person receiving care and their decision making at its heart.

- Is the guidance in chapter 13 on the authorisation, reviews and renewals processes clear?
  Somewhat unclear.
  The descriptions in Chapter 13 and 14 on how to work out which organisation is the Responsible Body for your authorisation are not sufficiently clear for independent hospices, which provide both in-patient and out-patient care, often across a wide geographical area, and will therefore have to refer to different Responsible Bodies depending on circumstances. Whilst we welcome the guidance for hospices in paragraph 14.11 and 14.12, further specific guidance for hospices and examples within the Code on this subject, which elaborate on the relationship between Responsible Bodies, place of care, continuing healthcare and where care is mainly provided, are necessary to train hospice staff on which body they should notify when.

We welcome the portability of the LPS as it means young people with complex and life limiting conditions will not need to be reassessed when they transition between children’s and adult services. This is particularly important as these young people may have already experienced significant change and uncertainty throughout their lives. However, we would welcome further clarity on whether an LPS authorisation is still valid if the person deprived of their liberty moves so that they are under the remit of a different Responsible Body, for example, if they move from staying at home in Manchester to a mental health unit in London.

- To ensure the independence of AMCPs, the Code provides a suggested model for a central AMCP team. Do you have any suggestions for how the model, as set out in chapter 18 of the Code, could be improved?
  Yes.

This suggested model currently lacks a clear system of governance or measures to ensure that AMCPs work to the same standards across England and Wales. Paragraph 18.11 mentions that a senior manager or practitioner should have responsibility for conduct, performance and allocation of AMCPs but it is
unclear whether AMCPs and their managers are ultimately responsible to the body that established their AMCP team or the local authority that manages AMCP approvals in their area.

Furthermore, for a model where AMCP teams can be established by either responsible bodies or local authorities to succeed, there needs to be clear national standards on how AMCPs determine whether authorisation conditions have been met as well as an assessment process that ensures these standards have been met, which is consistent across England and Wales.

This model can be improved upon by including a requirement that training for new AMCPs, and refresher training, imbues an understanding of the role liberty protection safeguards play in relation to palliative and end of life care and how a hospice environment may impact the LPS process.

- To what extent will chapter 20 and the Monitoring and Reporting regulations deliver effective oversight of the LPS?

Neither effective nor ineffective oversight of the LPS.

We would welcome greater clarity regarding how a standardised approach to monitoring will be implemented across Monitoring Bodies to ensure consistency across England and Wales. Further detail on what success in implementing the LPS looks like to a Monitoring Body would also be an asset to the Code.

Furthermore, recent research by the Nuffield Trust found that many hospices do not routinely capture information about patients, including ethnicity and other protected characteristics due to limited resources (Support at the end of life: The role of hospice services across the UK, May 2022). Typically, around one third of adult hospice and one fifth of children’s hospice funding is provided by the Government, with hospices having to make up the shortfall through bake sales, marathons and other fundraising endeavours.

The lack of a sustainable funding model for hospices makes it challenging for them to invest in innovation and reforms that benefit the wider system. For this reason, they will need sufficient support from Responsible Bodies and/or Monitoring Bodies to introduce the collection of National Minimum Data Set data. Resource demands associated with collecting this data should also be recognised in workforce planning and statutory funding hospice contracts.

**Putting the Code into practice and implementing the LPS**

- How clear is the LPS guidance in the Code and is there anything that you feel is missing?

The LPS guidance within the code is relatively clear, however, there is a significant gap in specific guidance on identifying the relevant Responsible Body for each authorisation. Hospices across England and Wales tend to deliver both in-patient and community palliative and end of life care across a mix of geographical areas. They are therefore likely to need to refer their identification of a deprivation of liberty to different Responsible Bodies depending on the setting and location in which they are working, where their patients are mainly being cared for and if their patients are in receipt of continuing healthcare. Some fantastic policy work within NHSE and the independent provider sector has resulted in informal guidance and knowledge sharing around when a hospice’s Responsible Body is a local authority and when it is an Integrated Care System. However, there is a crucial need for more detailed Government guidance on this subject, aimed at hospices, than is set out in paragraph 14.11 and 14.12 to pave the way for the smooth implementation of the LPS process in hospices in England and Wales.
A significant concern for Hospice UK is the consistency of the LPS process across England and Wales. There needs to be greater attention within the Code to how to ensure implementation is consistent in quality whilst still allowing for the local flexibility it has set out. For example, Government needs to monitor, endorse and provide high-quality LPS training to ensure that poor training is not being delivered to health and care staff in any locality.

- Is there any part of the Code where an existing scenario requires updating or a new scenario or best practice example is required altogether to help illustrate the policy?

Yes.

Further case studies where those being deprived of their liberty have a life limiting illness or are at end of life, including a specific case study that takes place within a hospice-setting would be valued.

- Will the Workforce and Training Strategy help your organisation prepare for the implementation of the LPS?

No.

Hospice UK has significant concerns that hospices in England will not be able to effectively train their staff in the new LPS process due to significant workforce shortages across the sector. These reforms also focus on incorporating LPS thinking as early as possible in existing care planning, disproportionately increasing the workload of the community-based workforce. Unfortunately, this is where the palliative and end of life care sector is most under strain. There have been over 100,000 additional deaths at home since the beginning of the pandemic, which has rapidly increased the need for palliative and end of life care in people’s own homes. Hospice UK would be happy to speak with officials in the Department of Health and Social Care about what measures they can take to respond to the hospice workforce crisis and increase capacity in the community to enable the effective implementation of the LPS.

The Workforce and Training Strategy and any additional centrally provided materials must be informed by the needs of non-NHS health and care providers implementing the LPS process, such as hospices. We are pleased to see a mention within the Strategy of the importance of understanding the number of people supported by independent hospital services, including building-based hospice services, in mapping the workforce needs associated with future LPS demand. However, Government must go further and ensure that centrally produced information and training resources are not overly focused on the LPS within NHS services.

Furthermore, either the social care provider’s implementation plan or the health implementation plan cited in this Strategy need to include significant consideration of the hospice sector and its needs. The work of children’s hospices must also inform policy related to expanding the LPS to 16 and 17 year olds. Government should encourage local areas to invite a local hospice representative to local planning/steering groups set up to prepare for the LPS launch.

The majority of hospices are small, community-rooted, primarily charitably funded organisations with limited resource. Therefore, they will need significant Government support to implement this Workforce and Training Strategy and ensure their staff are trained in the LPS process and their role within this.

- Does the Training Framework cover the right learning outcomes?

Whilst not prescribing any training and teaching methods, providers or assessment methods allows for the tailoring of LPS training to specific contexts, we are concerned it risks the development of poor quality
training. It is vital that Government ensures that all training on implementing the LPS in health and care settings is of high-quality and certified centrally. Only one third of adult hospice and one fifth of children’s hospice funding is from the Government and therefore the sector will require more support than most from HEE in order to develop and roll-out training specific to the hospice and palliative and end of life care sector.

As set out in a previous answer, a major concern is that hospices will struggle to implement the LPS, including reviewing and refining their current arrangements for defining and delivering LPS and mental capacity education, due to staff shortages and stretched services. A survey conducted by Hospice UK in Spring 2021, found a 11% vacancy rate in community-based nursing roles and 7% vacancy rate in hospice-based nursing roles in adult hospices (with 16% vacancy rates for hospice-based nursing associate and community-based healthcare assistant roles). These vacancies are representative of what is affordable within current funding rather than the level of staffing actually required to meet population need and, since this data was collected, the staffing situation has become much worse. More recent research reveals a 18.6% average vacancy rate for nurses and other non-medical care and support professionals (working at the equivalent of band 5-9) in children's hospices in England. Staffing and capacity is a significant barrier to the implementation of the LPS process within hospices and needs to be accounted for by central Government.

Finally, we would like to emphasise the importance of piloting the learning outcomes before they are embedded across England and ensuring a Quality Improvement approach is taken when developing all training on the LPS process to enable it to continue to improve and develop as it is rolled-out.

- Are there further data items needed in the National Minimum Data Set to provide effective oversight of the LPS?

No.

Reporting data to Responsible Bodies is a key area where small independent hospices will struggle to implement the LPS process and require extensive support from central Government. A recent report by the Nuffield Trust revealed systemic challenges in collecting data across the hospice sector, which are driven by capacity and resource constraints, and a lack of agreed definitions and standards for hospice activity (Support at the end of life: The role of hospice services across the UK, May 2022). Many hospices do not have the infrastructure in place for the LPS data collection and will need support from Government to improve their data collection and handling. Furthermore, hospice statutory funding contracts and workforce planning must recognise the resource demands associated with collecting this data. Responsible bodies should also seek to make it easier and less time consuming for small organisations, such as hospices, to collect this data by aligning their requests with other requests for data and information these organisations receive from their local systems.

Hospice UK would also welcome clarification on whether this data set will be anonymous and how it will be aggregated and reported.